

ASSOCIATION OF
COMMUNITY
CANCER CENTERS

FINANCIAL
ADVOCACY
NETWORK

Shared Decision Making for Financial Advocates

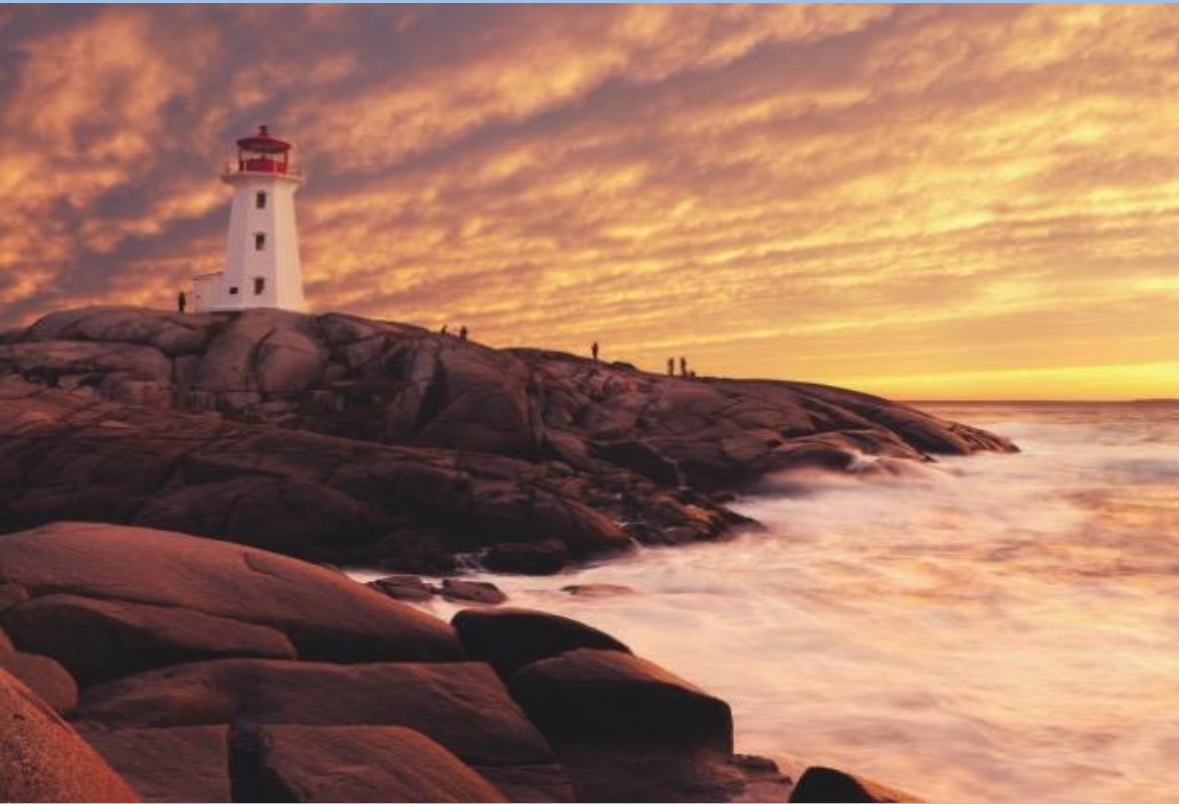
ACCC Financial Advocacy Network Summit
August 16, 2018
Downtown Washington DC



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Financial toxicity and cost of care conversations.

Alan Balch, PhD
ACCC Financial Advocacy Network Summit
Washington, D.C.
August 16, 2018



OUR MISSION

Patient Advocate Foundation is a national 501(c)(3) organization that seeks to safeguard patients ability to access care, maintain employment and preserve their financial stability relative to their diagnosis of chronic, life threatening or debilitating diseases.

Funded Research

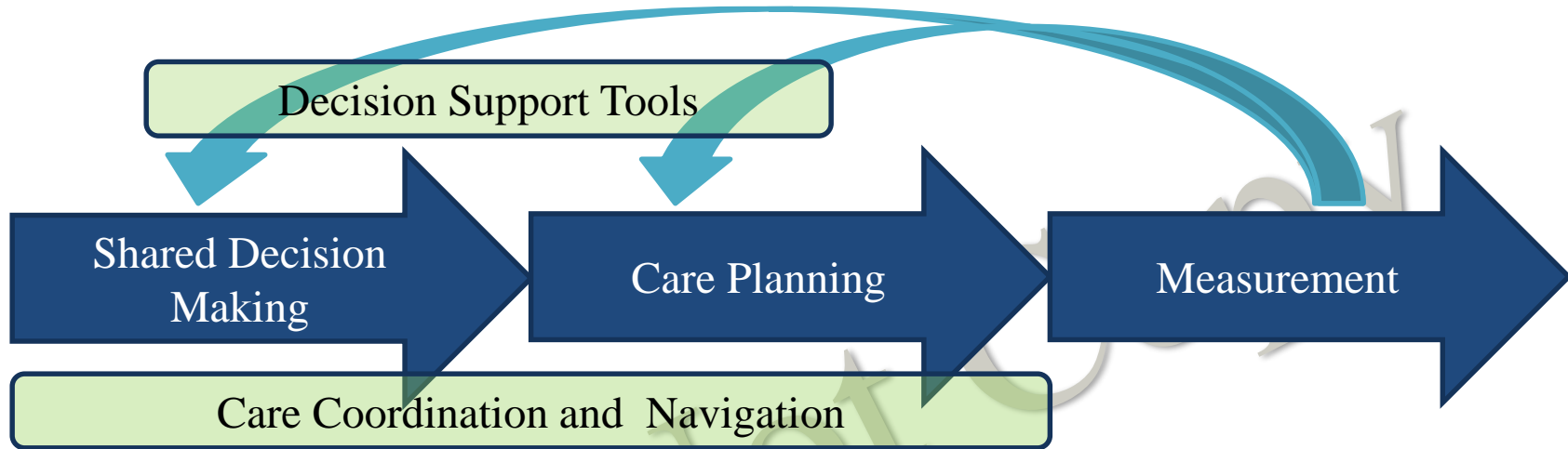


Roadmap to Consumer Clarity in Health Care Decision Making


Robert Wood Johnson Foundation

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Feedback Loop for Rapid Learning Environment



- Expression of personalized goals, needs, and preferences matched against personalized treatment options
- Adjusted for certain variables that may impact appropriate treatment selection.
- Develop a goal concordant care plan that includes identifying social support and care navigation needs
- Data collection and sharing to track adherence and progress
- Patient Reporting on QoL, functional status, health status and safety
- Care coordination and navigation especially for high cost and high needs patients

Survey Methodology

- Survey open between May 2, 2018 and May 25, 2018
- Eligibility was dependent on receiving a service from PAF during the 2017 calendar year.
- Respondents representative of PAF patient population.
- Response rate of 14% and total of 1,371.
- Presented data is from 568 patients with any cancer diagnosis and 269 diagnosed with HIV/AIDS.
- 70% of HIV/AIDS patients diagnosed more than 10 years ago compared to 10% of cancer patients.
- 53% of cancer patients diagnosed within the last two years compared to 5% of HIV/AIDS patients.

Prevalence & Severity

In the past year, have you experienced a financial hardship due to the cost of your medical care?

- Cancer 70%
- HIV 58%

If yes, then how severe would you say this financial hardship was for you on a scale of 1 to 10 (10 is most severe)?

Cancer

8 = 16%

9 = 12%

10 = 32%

60%

HIV/AIDS

8 = 19%

9 = 17%

10 = 21%

57%

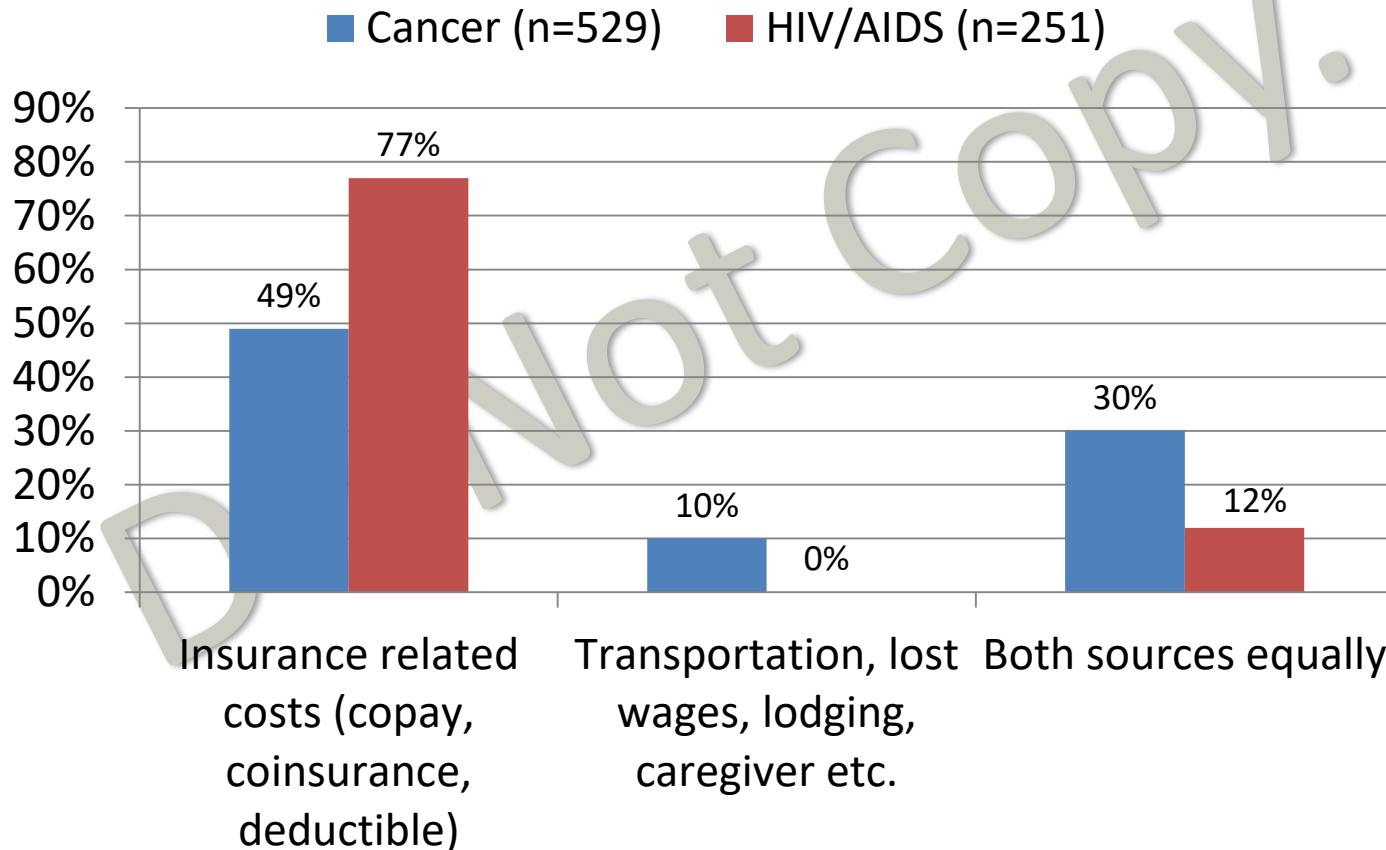
Sources of Hardship

Percentage of respondents who experienced financial hardship that identified the following as a specific healthcare cost related to treatment that contributed the most to their hardship:

	Cancer (n=365)	HIV/AIDS (n=139)
Office visits to specialists	44%	40%
Radiology services	40%	9%
Oral medication	38%	73%
Lab testing services	36%	24%
Loss of income (work)	34%	8%
Transportation/travel costs	29%	8%
Infused medications	29%	6%
Visits to primary care team	24%	24%

Out of Pocket Expense

Thinking about the last 12 months and the costs you have experienced related to your medical care – please pick the type of expenses that were the greatest source of financial strain to you.



Treatment Experience

What type of treatments or services have you had in the past 12 months?

List of possible treatments or services	Cancer (n=521)	HIV/AIDS (n=241)
Drug therapy by mouth or through a needle	76%	64%
Post treatment follow-up	37%	24%
Planning of your treatment	35%	4%
Help dealing with side effects of treatment	36%	18%
Surgery	33%	1%
Radiation therapy	26%	1%
Diagnosis	22%	7%
Waiting/watching if treatment is needed	9%	3%
Alternative or complementary therapy	9%	4%
Other	9%	11%

Comparing Costs

Thinking about the service you received, on a scale from 1 to 5, where 1 is very unaffordable and 5 is very affordable, how affordable were the costs you had to pay?

Responses on the unaffordable end of spectrum (1 or 2) by service:

Cancer

68% Diagnosis

59% Drug therapy

52% Surgery

52% Radiation therapy

HIV/AIDS

37% Diagnosis

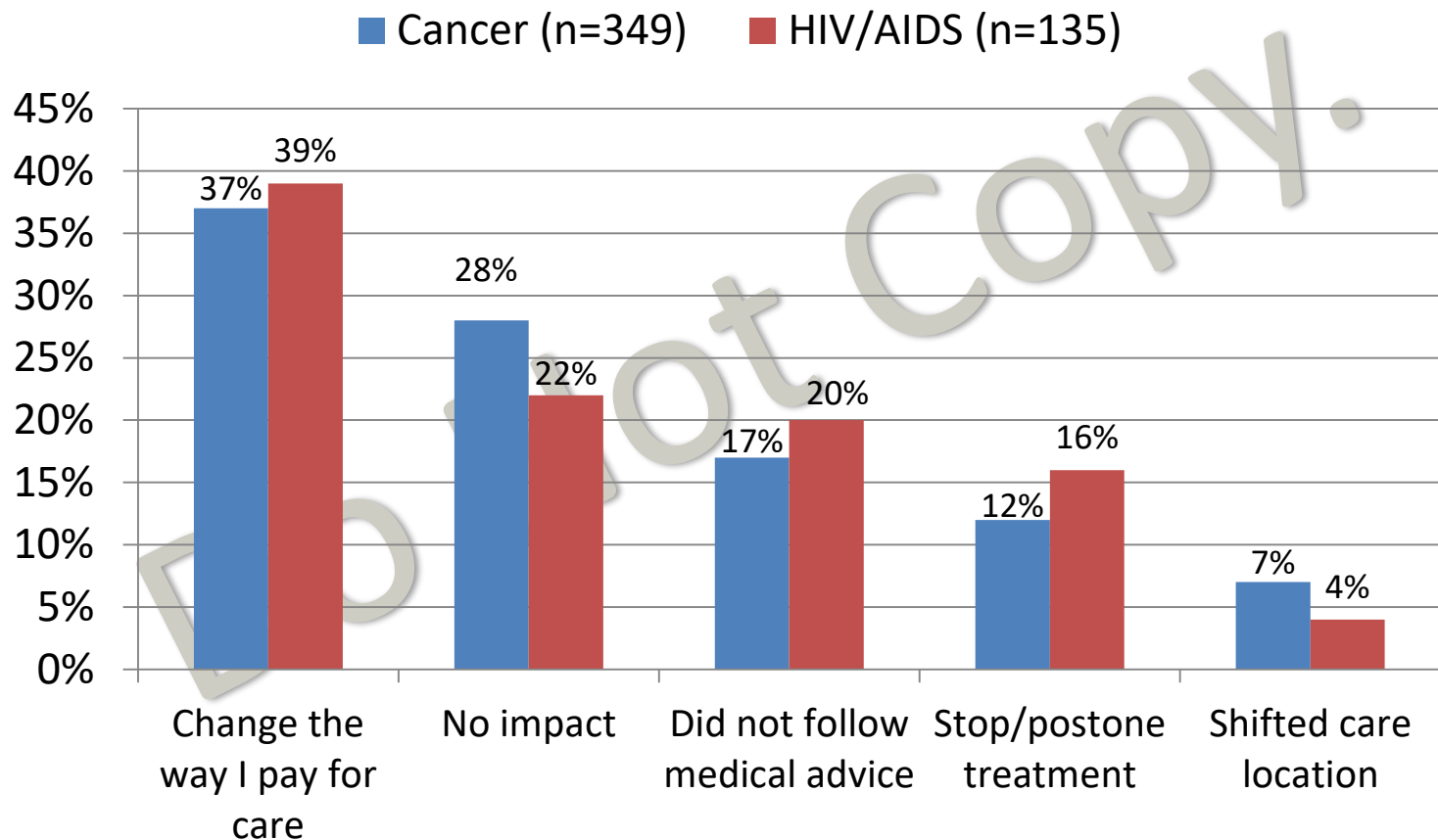
69% Drug therapy

100% Surgery

100% Radiation therapy

Impact on Medical Care

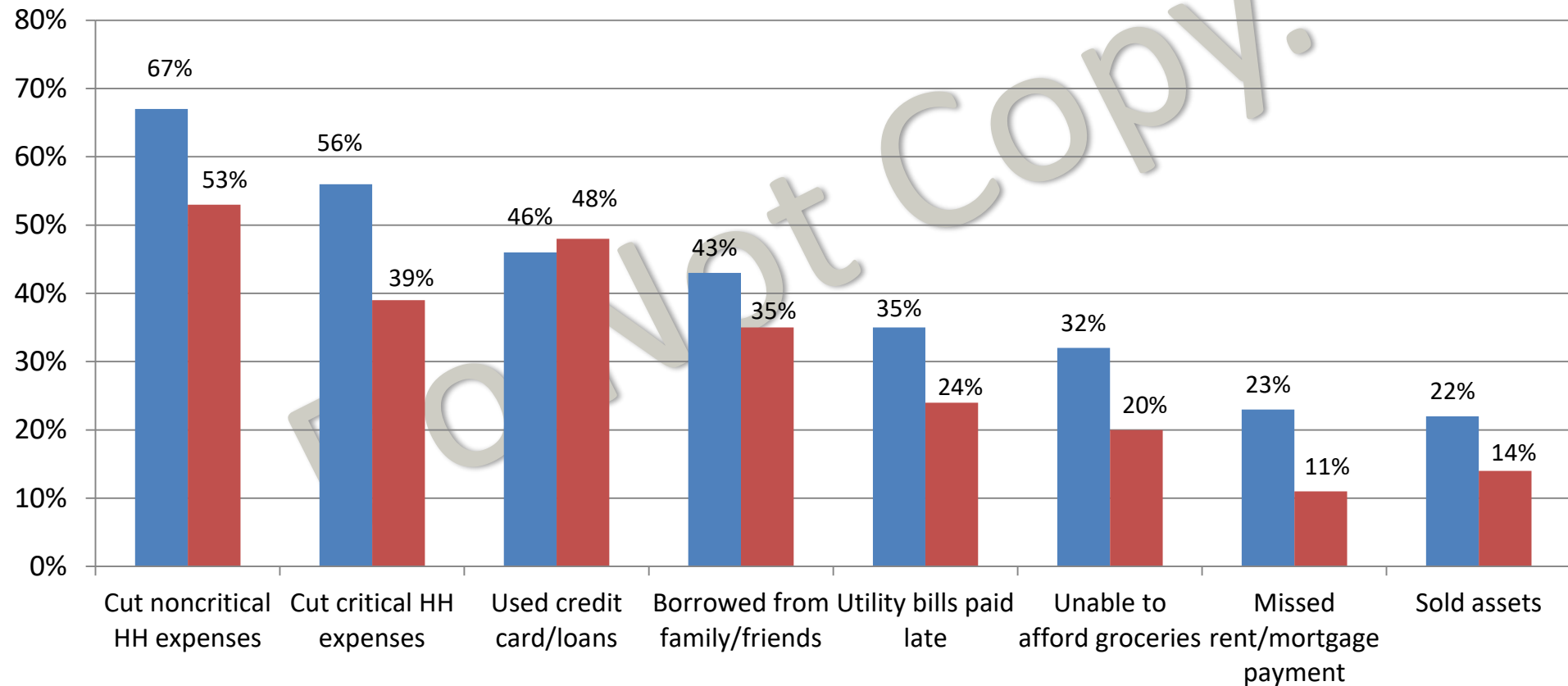
If you experienced a financial hardship, then what impact did it have on your medical care in the last 12 months?



Impact on Finances

What impact did the financial hardship have on your financial situation in the last 12 months?

■ Cancer (n=357) ■ HIV/AIDS (n=135)



Financial Toxicity: Material Hardship Screening

On the Edge of a Cliff

Tucker Seeley's Research Lab at USC identified measures to help capture issues with making ends meet

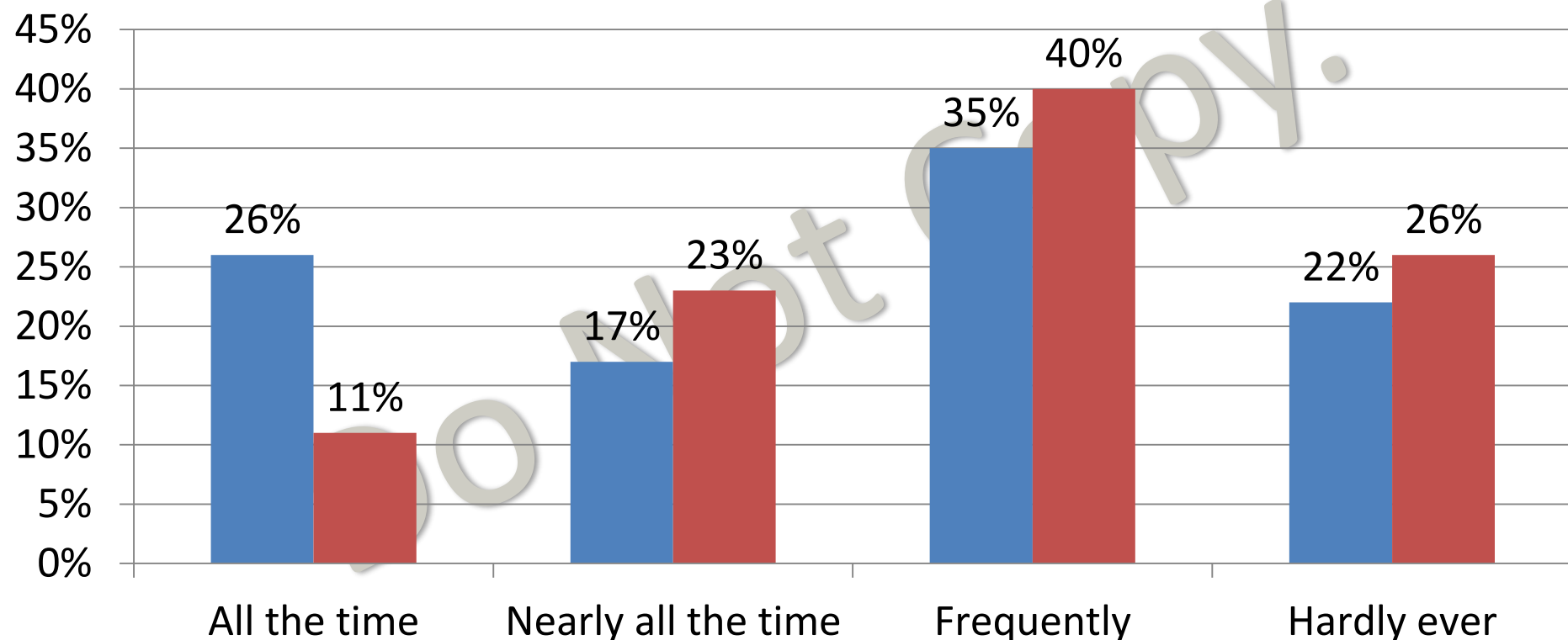
- 38% said it was very difficult and 30% said it was difficult to live on their total household income right now.
- 13% said they pretty much and 17% said a great deal that they anticipate experiencing actual hardships such as inadequate housing, food or medical attention in the next two months.
- 18% said they pretty much and 18% said a great deal that they anticipate having to reduce their standard of living to the bare necessities of life in the next two months.

Vinokur AD, Price RH, Caplan RD. Hard times and hurtful partners: How financial strain affects depression and relationship satisfaction of unemployed persons and their spouses. Journal of Personality and Social Psychology. 1996;71(1):166-179.

Financial Stress

Thinking back over the past month, how often have you had serious financial worry?

■ Cancer ■ HIV/AIDS



Creed PA, Macintyre SR. The relative effects of deprivation of the latent and manifest benefits of employment on the well-being of unemployed people. *Journal of Occupational Health Psychology*. 2001;6(4):324-331.

Material Hardships

- 33% said there was a time when they were not able to pay the rent or mortgage on time in the last 6 months.
- 15% said they had to go without health care at some point in the last 6 months because they didn't have a way to get there.
- 22% said they had received during the past 6 months a letter from a utility (gas/electric/oil) company threatening to shut off service to the house for not paying bills.
- 43% said that they often or sometimes worried during the past 6 months whether their food would run out before they got money to buy more.

*Kira Bonham, MD, MPH Dana-Farber/Boston Children's Cancer and Blood Disorders Center
HMH Concrete Resource Needs Screen*

Work Disruptions

Percentage of respondents reporting a work disruption for themselves or spouse during the last year:

	Cancer	HIV/AIDS
Experienced negative work changes	24%	17%
Laid off or dismissed	16%	8%
Changed jobs for a worse one	8%	6%
Other involuntary loss of work	27%	17%

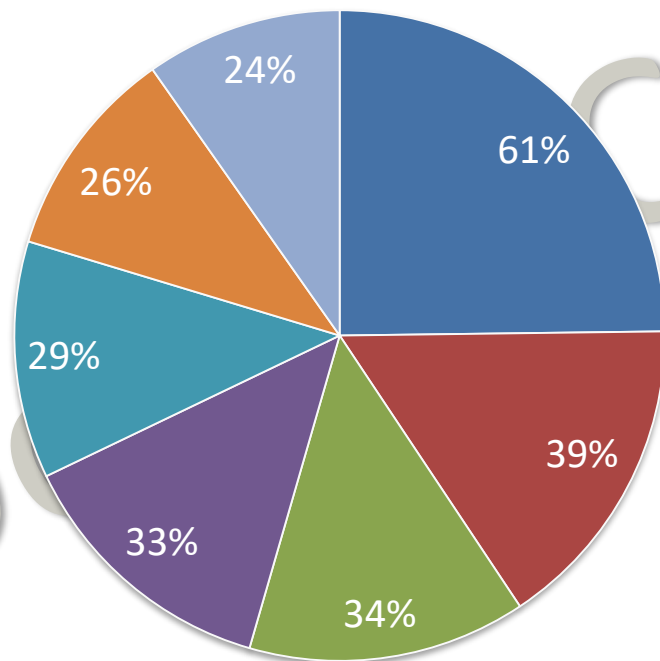
Parke RD, Coltrane S, Duffy S, et al. Economic stress, parenting, and child adjustment in Mexican American and European American families. Child Development. 2004;75(6):1632-1656.

Financial Impact on Care

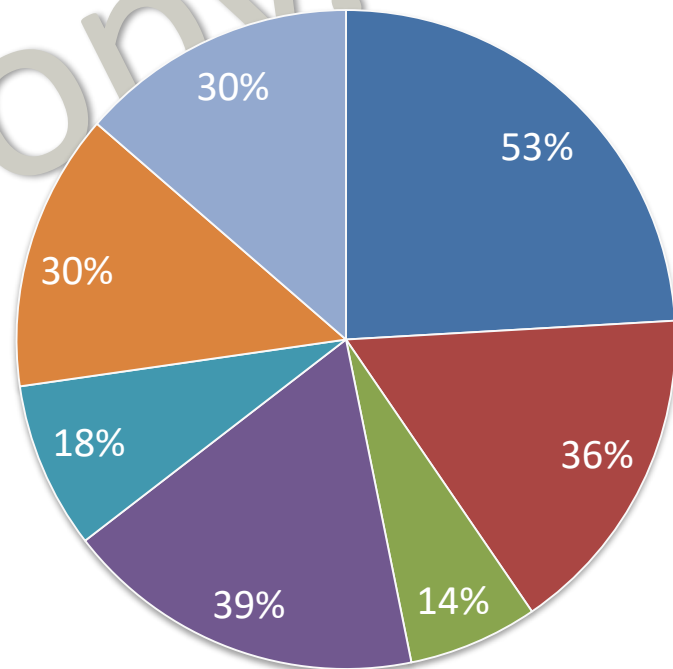
Have you had to do any of the following in the past 12 months?

- Dip into savings to pay for a medical visit, test or procedure
- Made the decision to pay medical bills instead of other montly expenses
- Had to consider cost of transportation related to medical care
- Tried to find a lower cost option for a medical test or procedure
- Had to consider the financial costs of taking time off work for medical care
- Skip or delay a needed medical procedure due to costs
- Skip a dose of prescription medication or stop taking it

Cancer (n=469)



HIV/AIDS (n=222)



Cost of Care Conversations Practical Experiences

Care Conversations

How much did a doctor (or health care provider) talk with you about the reasons you wanted to have the treatment you chose?

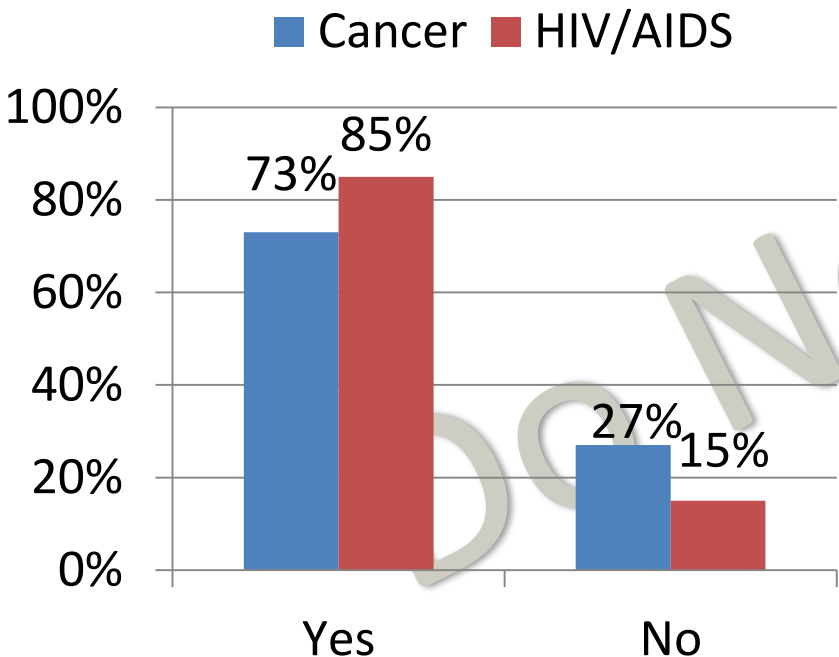
	Cancer	HIV/AIDS
A lot	72%	67%
Some	19%	26%
A little	7%	2%
Not at all	2%	4%

How much did a doctor (or other health care provider) talk with you about reasons you might not want to have the treatment you chose?

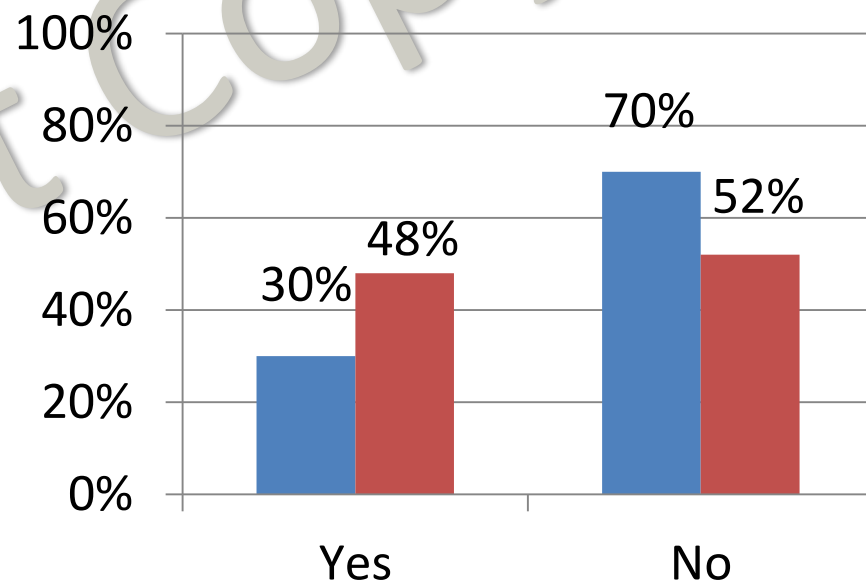
	Cancer	HIV/AIDS
A lot	22%	16%
Some	24%	24%
A little	16%	11%
Not at all	38%	49%

Treatment Conversations

Did any of your doctors (or health care providers) explain that there were choices in what you could do to treat your condition?

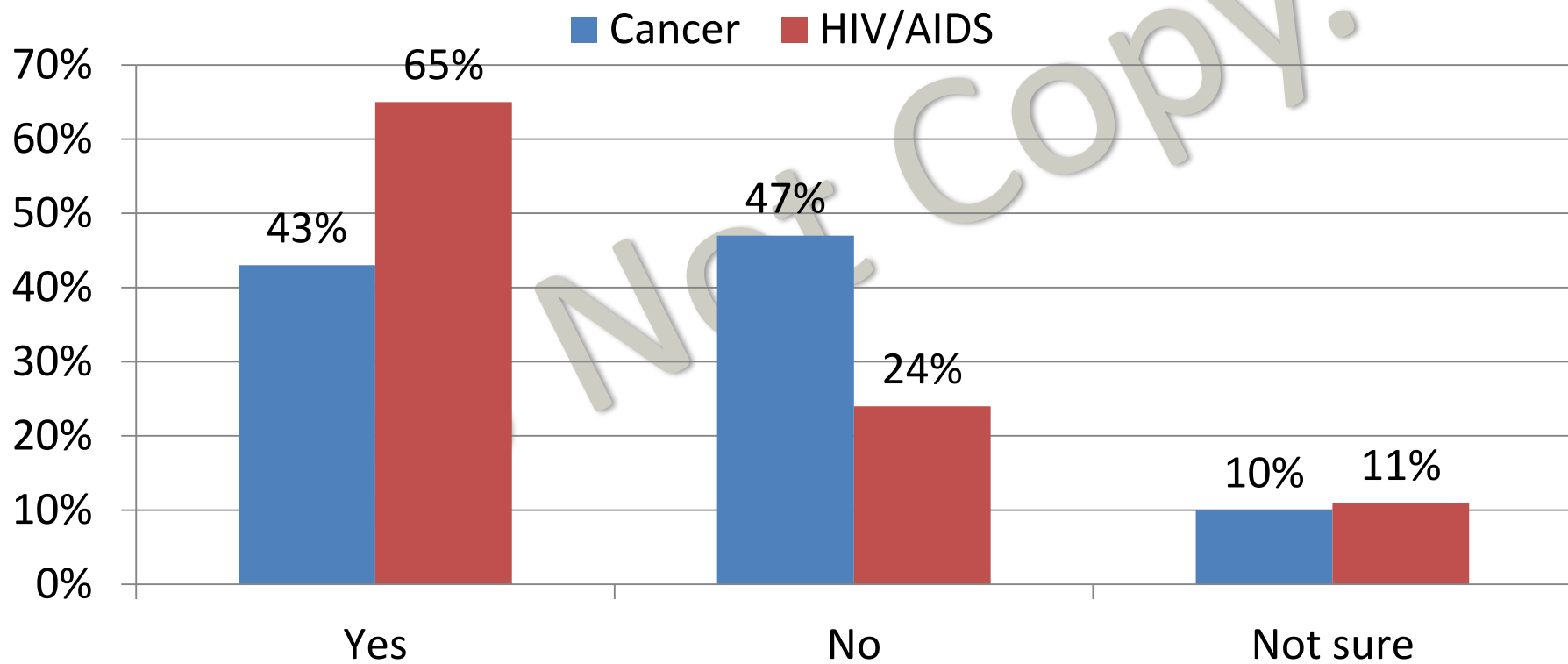


Did any of your doctors (or health care providers) explain the costs associated with the treatment options you discussed?



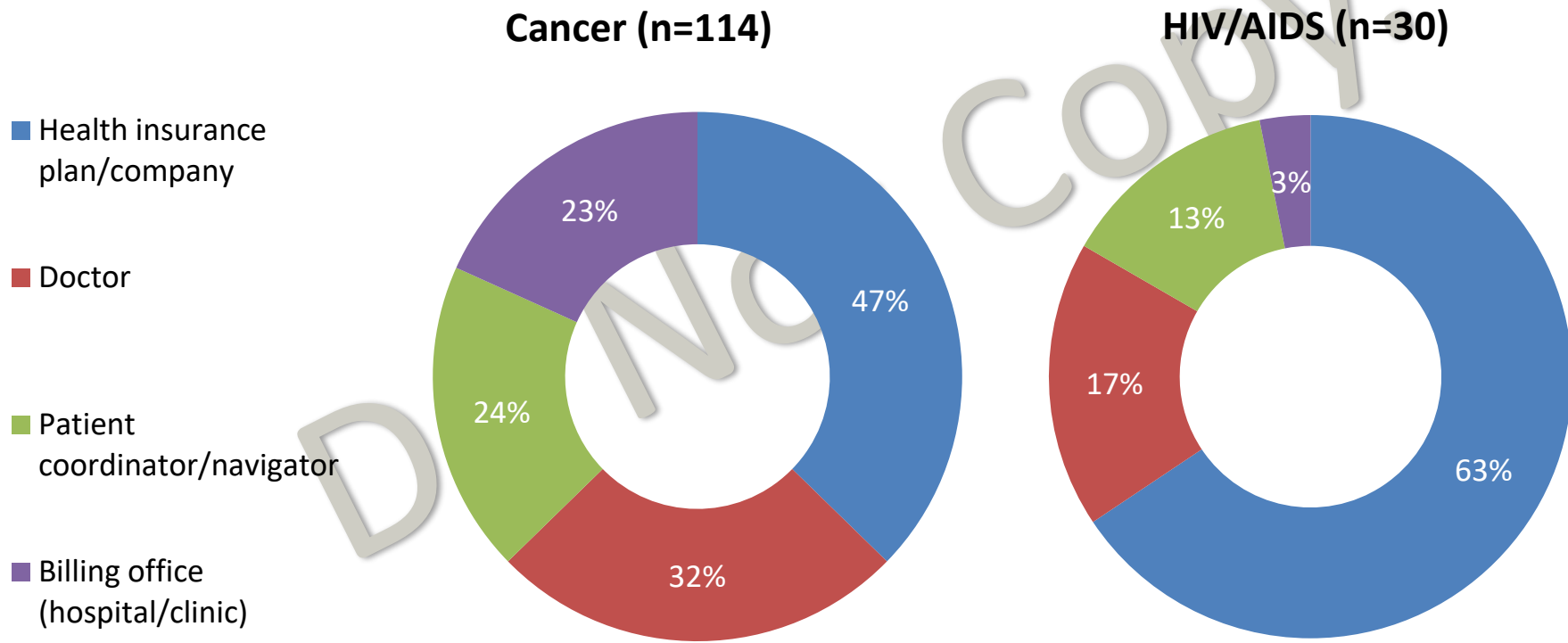
Determining Cost of Care

Prior to receiving treatment, did you attempt to determine the specific costs you were going to have to pay for the treatment you selected?



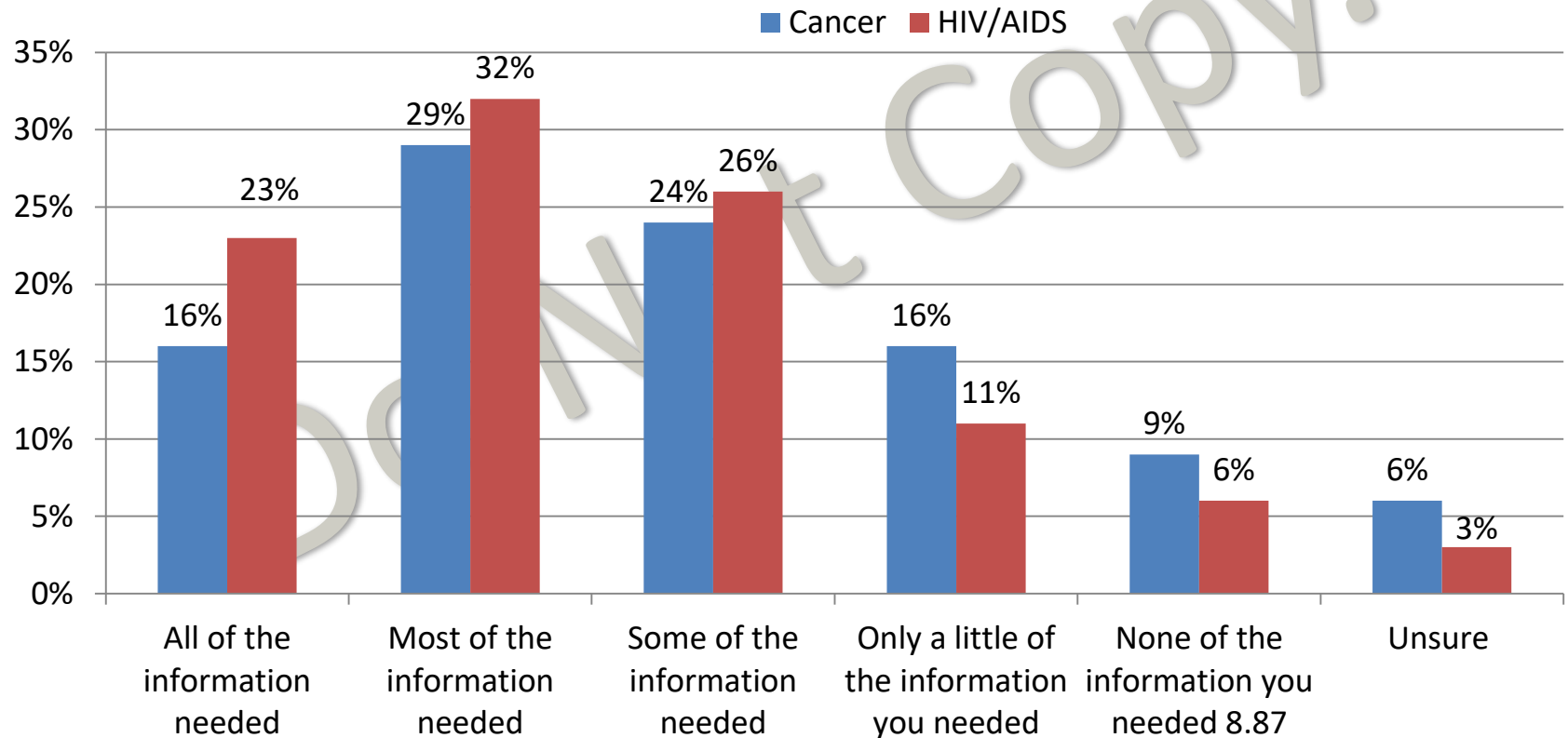
Cost of Care Information

Where did you attempt to obtain the information you needed about costs of your treatment?



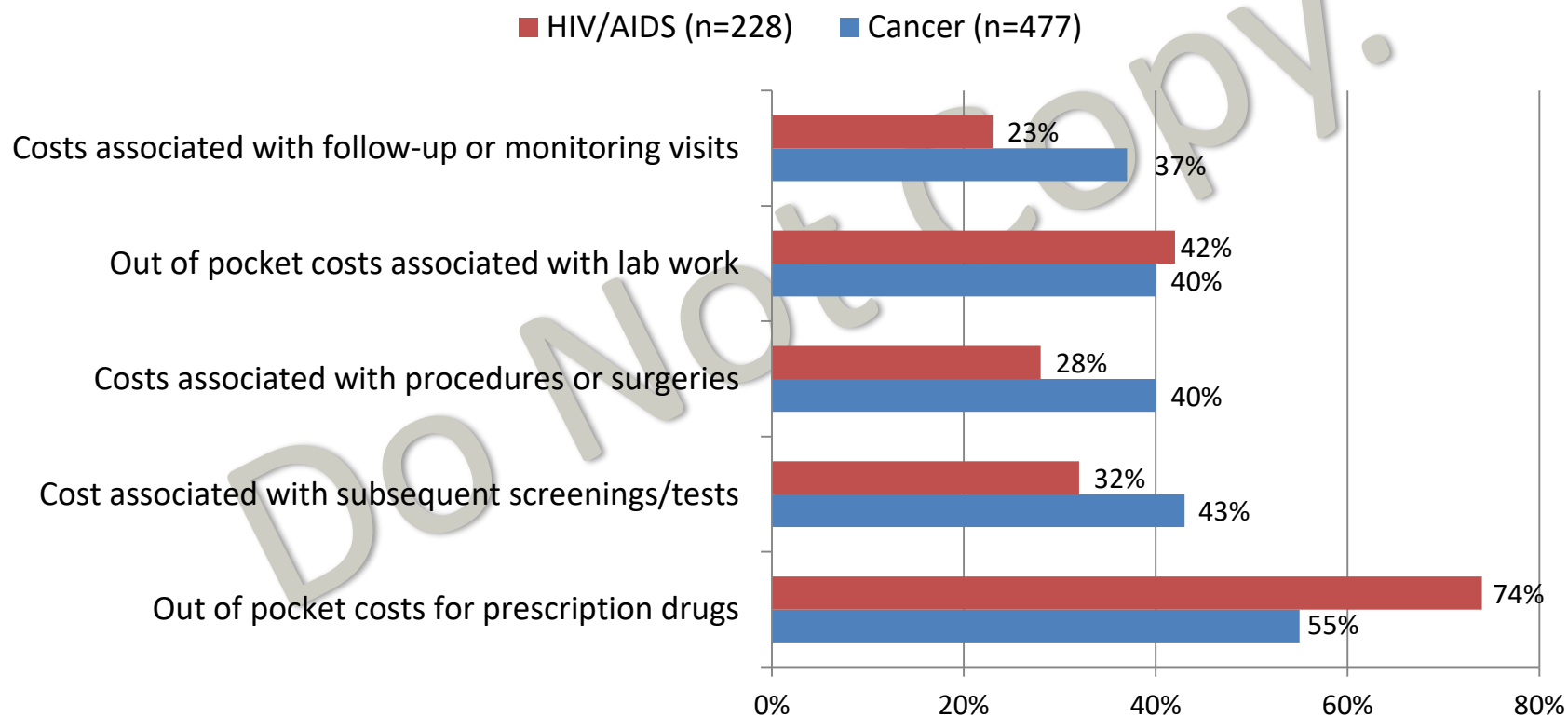
Cost Conversations

Thinking about the medical professionals you have seen in the past 12 months, to what extent do you feel that you had enough information about how different treatment options would impact your out of pocket costs to choose the one that best fit your needs and preferences?



Need for More Information

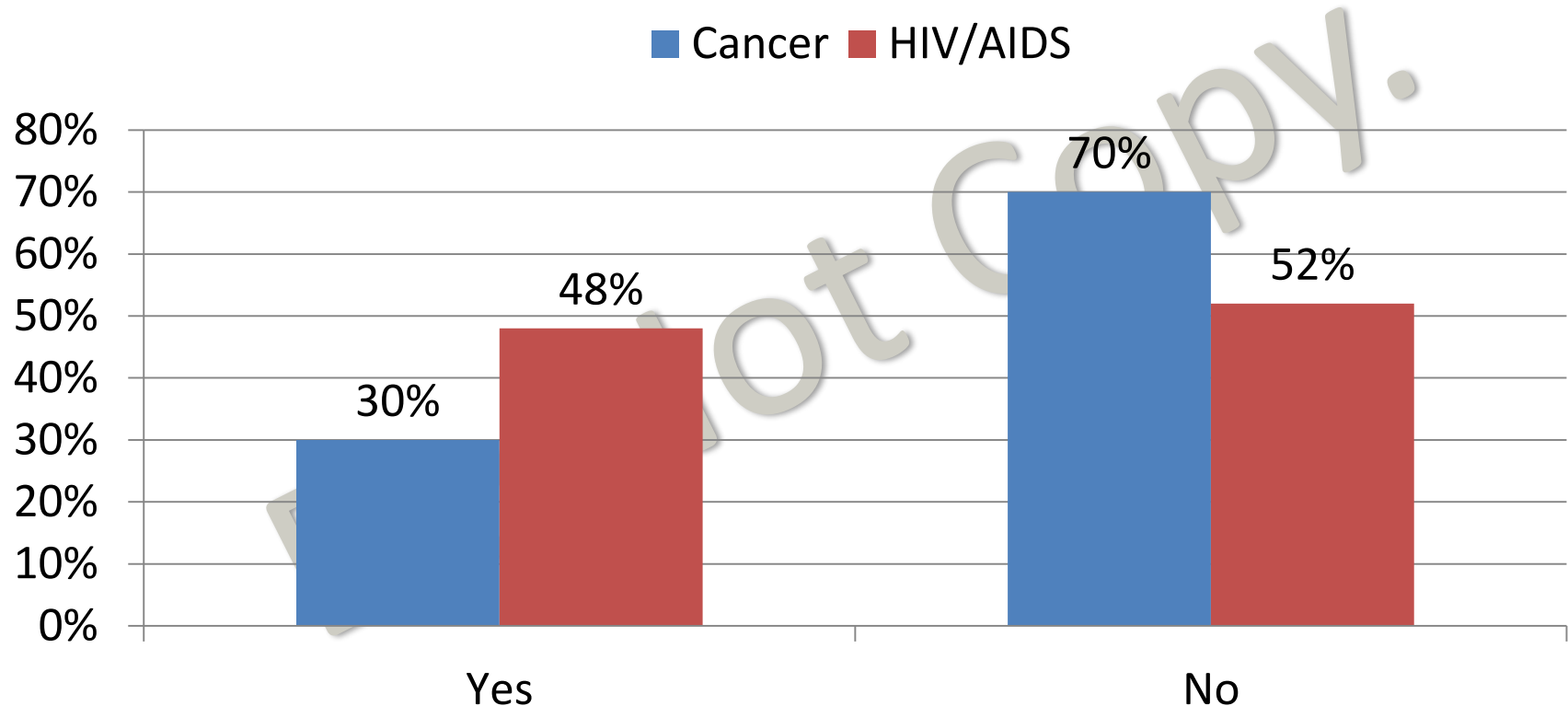
In what areas do you feel that you needed more information about the costs associated with your care?



Cost of Care Conversations: Normative Preferences

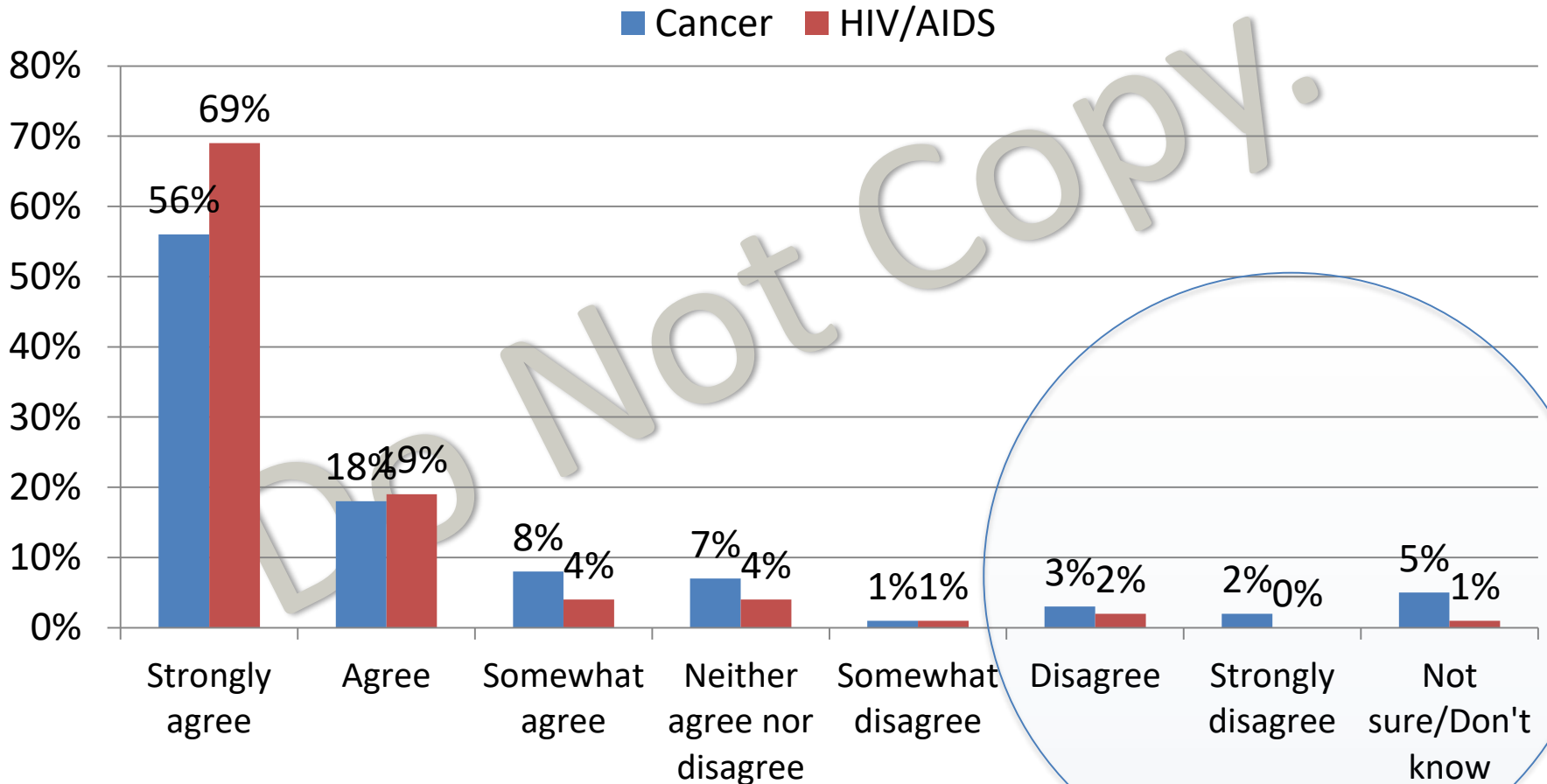
Need for More Information

Did any of your doctors (or health care providers) explain the costs associated with the treatment options you discussed?



Transparency & Cost

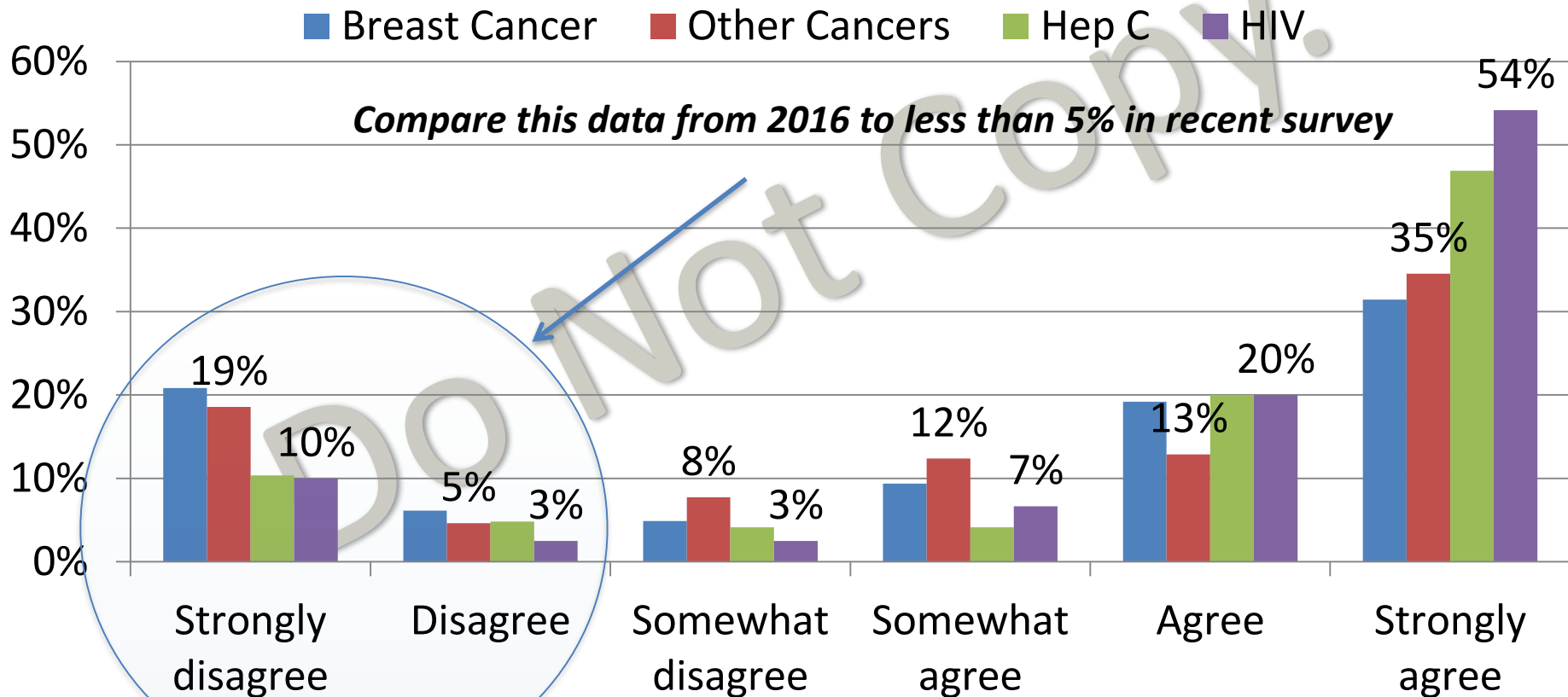
To what extent do you agree or disagree with the following statement:
“Knowing the cost I am going to pay out of pocket for my care is important when it comes to making decisions about what treatments I should use”.



Transparency & Cost

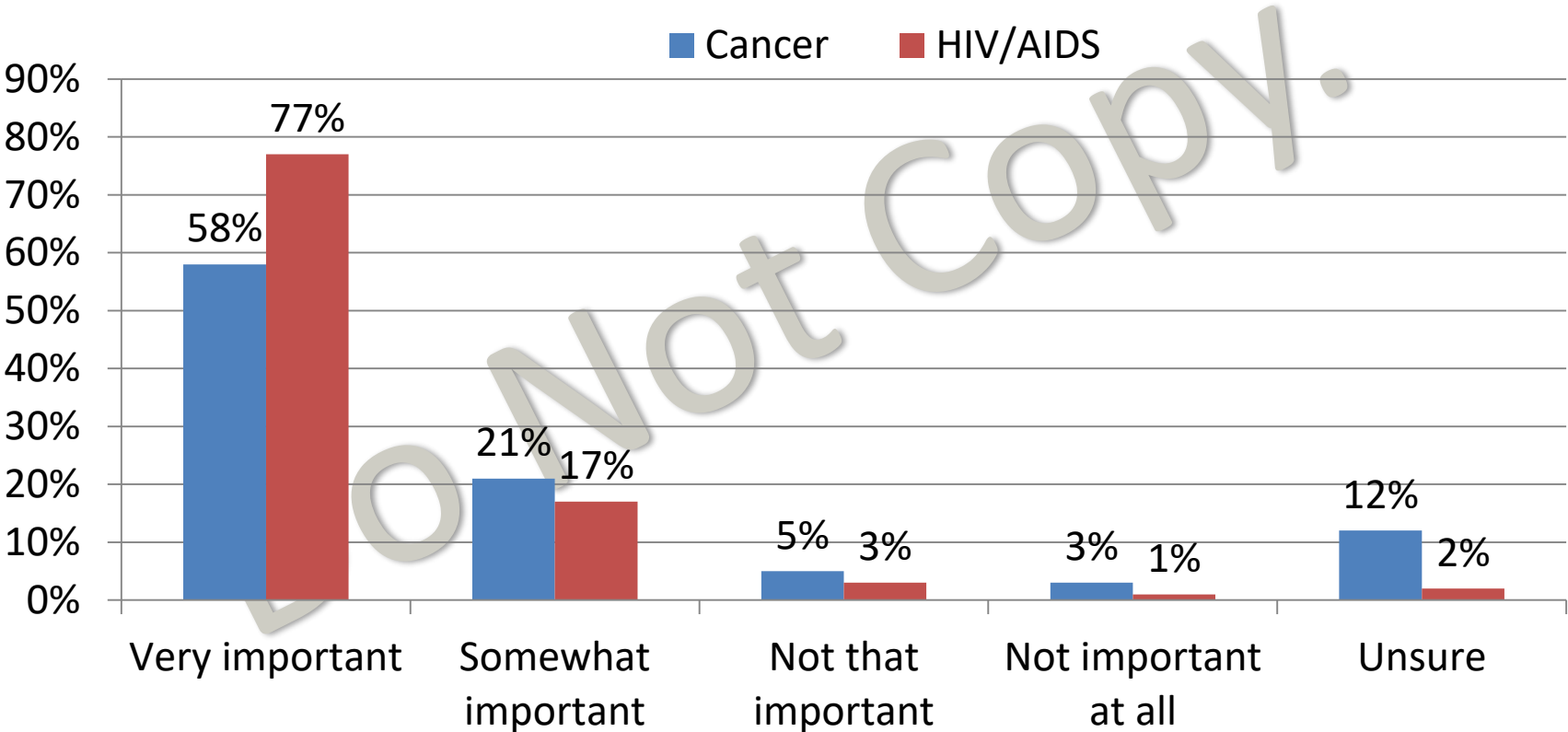
To what extent do you agree with the following statement:

“Knowing the cost I am going to pay out of pocket for my care is important when it comes to making decisions about what treatments I should use”.



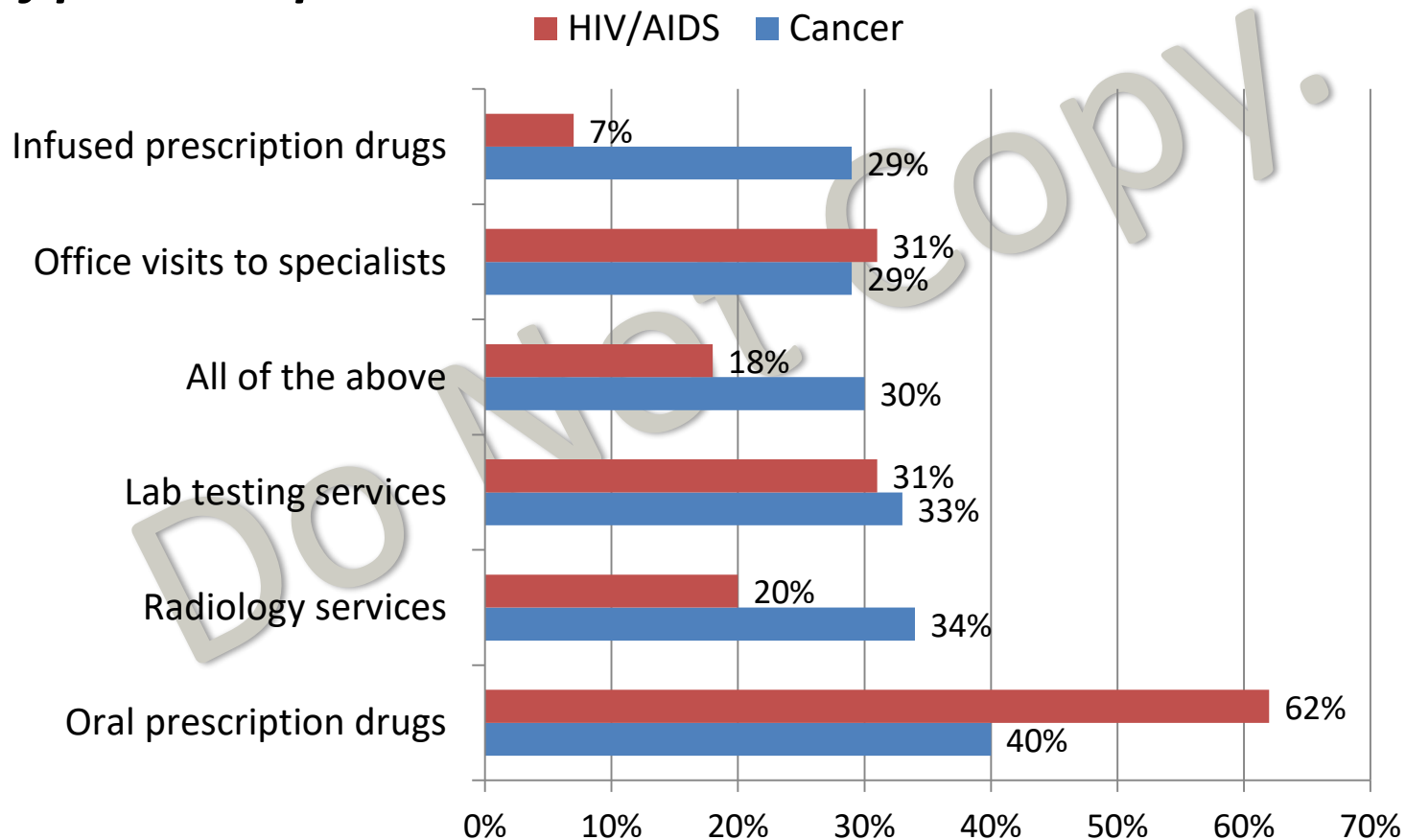
Transparency & Cost

How important is it for you to discuss with your medical provider the cost you have to pay for your medical care?



Need for Cost Information

Which specific types of medical costs would you want to know more about and be more prepared for when it comes to your likely out of pocket expenses?



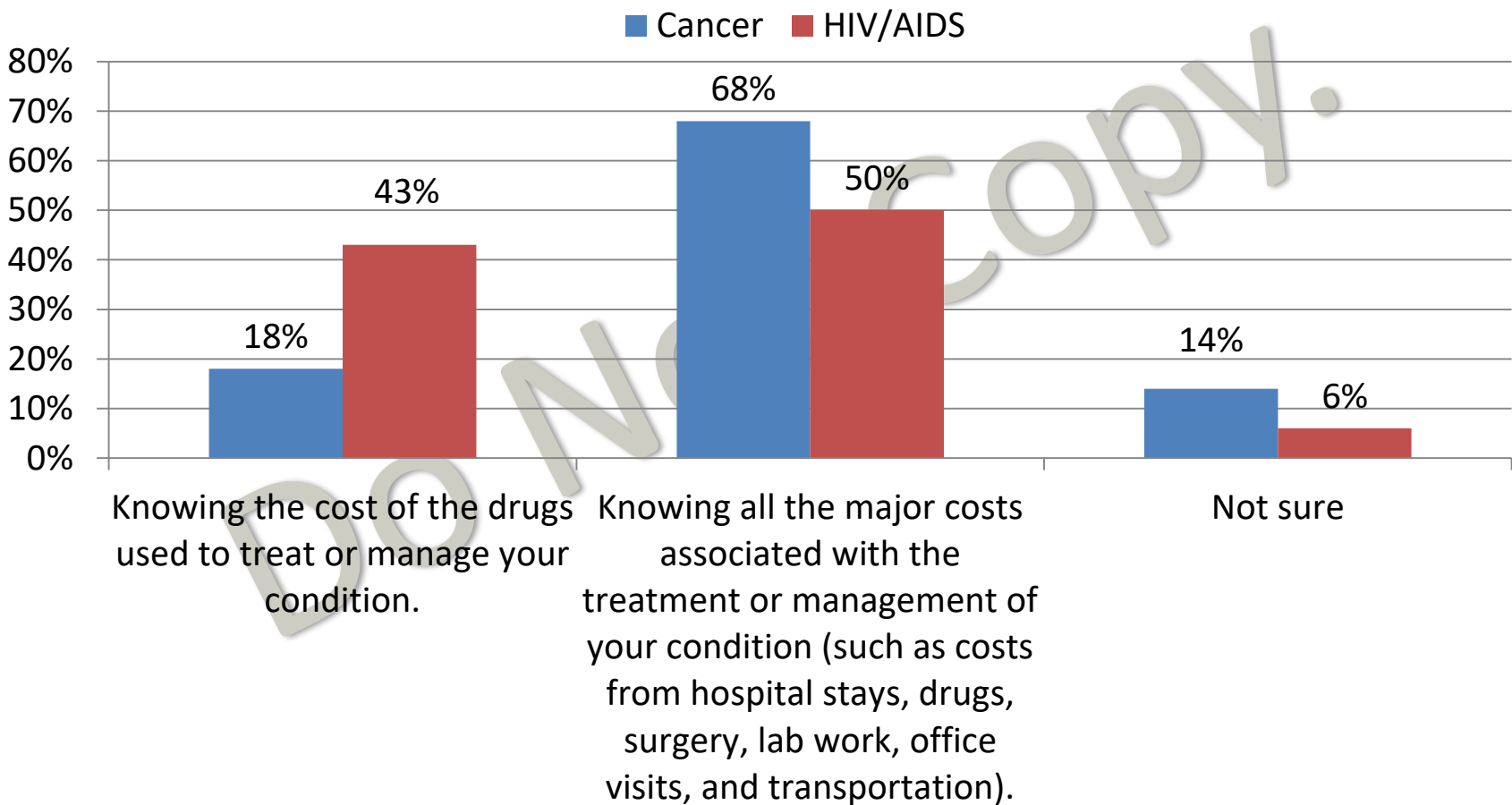
Comparing Costs

When asked about how helpful specific financial information would be to choosing between treatment options:

	% Extremely Helpful	
	Cancer	HIV/AIDS
Knowing the specific dollar estimates for my out of pocket costs based on my insurance benefits including deductibles, copayments, and coinsurance	58%	68%
Knowing the “list price” or “average price” of the drugs involved in your treatment based on the prices used to sell the medication to insurance companies, pharmacies, and physicians (not your out of pocket cost)	45%	50%
Knowing about potential costs related to things not covered by traditional insurance like transportation, lodging, missed work, and child care	43%	39%
Knowing the average amount paid for the treatment by patients with my diagnosis based on studies of the treatment’s out of pocket costs using data from thousands of patients	40%	43%
Having a point system for a specific treatment with 1 being least affordable and 5 being most affordable based on the experience of medical professionals	34%	40%

The What and the Who?

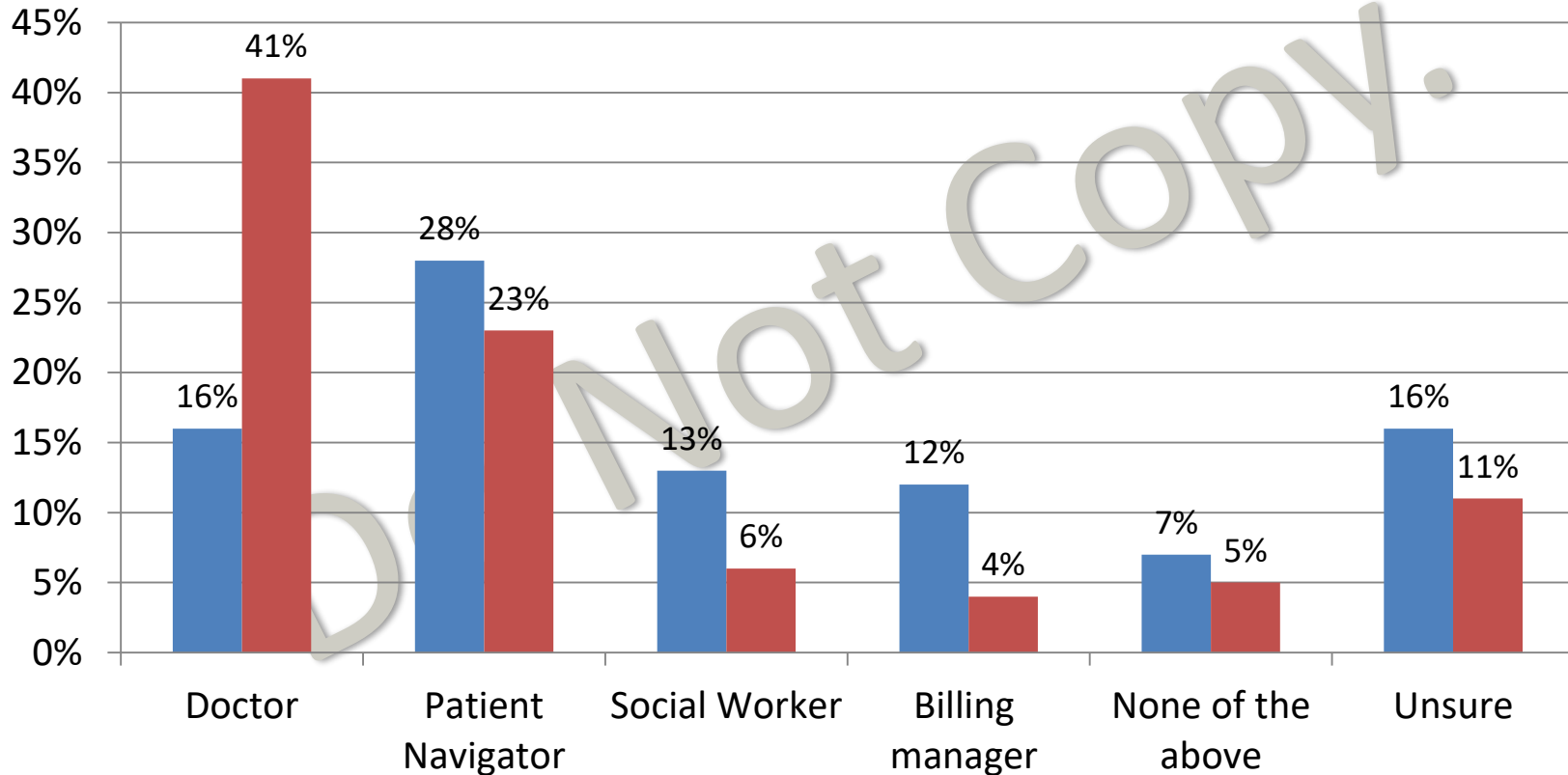
Of the two options below, which do you think is more important for your treatment decisions?



Cost Conversations

Generally speaking, who do you prefer to discuss the costs associated with your treatment with?

■ Cancer ■ HIV/AIDS



**Responses less than 5% were omitted*

Cost Conversations

Indicate the level of importance each of the following statements has to you when having conversations with your medical provider about the costs of your medical care that you would have to pay:

The top choices rated as being very important:

	Cancer	HIV/AIDS
Knowing that there may be resources or options for reducing costs	80%	79%
Knowing the questions you need to ask	73%	69%
Feeling confident that the provider will still provide you with the best care if you ask about costs	72%	72%
Having access to information about the costs associated with the care you need	68%	67%

Thank you!

Alan Balch

Patient Advocate Foundation
Chief Executive Officer



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